Workshop F: Evaluation of Prevention Programs —Mary Glenn Fowler and Mary Lou Lindegren, chairs

Goal: To discuss with states the types of data that should be collected by states as part of monitoring and impact evaluation of the Perinatal HIV Prevention Program

Objectives

- Assist states in collecting data regarding the monitoring and impact of their programs on perinatal HIV prevention
- Discuss different Centers for Disease Control and Prevention (CDC) and state data collection instruments already available and share states' experiences using these instruments
- Discuss approaches to collection of data on specific targeted perinatal prevention programs
- Discuss how monitoring and impact tools can be used in an ongoing manner to improve program efficiency and outcomes

Guiding Principles of Evaluation — Mary Glenn Fowler, CDC

This workshop begins the process of sharing strategies and reviewing state approaches. CDC is creating an internal evaluation group with ongoing meetings. Input by states is important. A summary of evaluation tools and methods should be ready by midsummer.

Evaluation

- Should be conducted within the context of ongoing surveillance and data collection.
- Should use targeted programs that evaluate impact on women and children.
- Should use a standardized approach to data collection of key variables, not necessarily all survey instruments.

Strategies/Approaches/Resources

- Use of pediatric enhanced surveillance and other data sets available in states
- Targeted perinatal programs
- Summary progress reports (provided to CDC by grantees)
- Surveys to evaluate materials and educational packages developed by national organization partners

Summary of State Proposals —Abu Abdul-Quader, CDC

All grantees target some or all populations specified in Request for Proposal; i.e., women consumers, providers, public health agencies.

Targeted women include women who are in the general population, of childbearing age, pregnant,

HIV-infected, substance abusers.

Intervention strategies targeting women include
- Outreach
- Social marketing
- Testing and referrals
- Prevention case management
- Enhanced case management
- Risk assessment

Health care provider interventions include
- Information dissemination
- Education
- Training workshops
- Lectures and seminars

Interventions targeting others—health department staff, staff at drug treatment facilities, and sexually transmitted disease (STD)/HIV surveillance staff— include
- Training and education
- Collection and analysis of data
- Review of medical record
- Cross-training of staff from Women, Infants, and Children (WIC), Maternal and Child Health (MCH), and drug treatment programs

In addition, other activities include collaboration with various agencies, building coalitions, establishing linkages with the community.

Epidemiologic Profiles and Datasets Already Available for Development and Assessment of Epi Profile — Mary Lou Lindegren, CDC

Enhanced Perinatal HIV Surveillance
Thirty-two states currently have named HIV reporting. Funding for enhanced perinatal surveillance is in 22 of those states with the highest seroprevalence. Enhanced perinatal surveillance is an expansion of Surveillance to Evaluate Perinatal Prevention (STEP), a surveillance project initially implemented in four states (NJ, SC, MI, LA) in 1996 and was instrumental in the recent Institute of Medicine (IOM) report findings.

- Enhanced ascertainment of mother-infant pairs: active case findings at pediatric sites and obstetric hospitals, matching of HIV/AIDS registry to birth registry, laboratory reporting, and women pregnant at the time of report
- Systematic ascertainment of data from multiple sources: maternal HIV clinic, prenatal, labor/delivery, newborn and pediatric records, standard case report form and supplemental data collection form, active follow-up of exposed infants every 6 months for infection status

- Collaboration with programs (HIV prevention, MCH, substance abuse)

States without HIV Surveillance
- Alternate methods to collect data on HIV-infected mothers and their newborns—facility-based collection of enhanced perinatal HIV surveillance data, with Institutional Review Board (IRB) approval at those facilities
- Standard case report form and supplemental data collected on HIV-infected mothers and exposed children at those selected facilities (prenatal care, HIV testing, ART)

Characterizing the Local Perinatal HIV Epidemic and the Impact of Prevention, Using HIV and All Available Sources of Surveillance Data
- Prenatal care
- General population [birth certificates, Pregnancy Risk Assessment Monitoring System (PRAMS)]
- HIV-infected women (enhanced perinatal HIV surveillance)
- HIV counseling and testing
- All pregnant women [birth certificates, PRAMS, audit of hospital prenatal records at Emerging Infections Program (EIP) sites]
- HIV-infected women (enhanced perinatal HIV surveillance)
- Use of antiretroviral therapy—ART, enhanced perinatal HIV surveillance, Survey of Childbearing Women (SCBW)
- Outcome of child (enhanced perinatal HIV surveillance)
- Other sources [Medicaid, Supplement to HIV/AIDS Surveillance (SHAS), HIV counseling and testing, Pediatric Spectrum of Disease (PSD)]

States are in different stages of data collection from some or all of these sources. New Jersey and New York City have enhanced perinatal HIV surveillance data already and other data sources as well, and those will be presented during this session.

Here is an example of Connecticut Surveillance Data.
- Pediatric HIV surveillance data, including perinatally exposed children
- Survey of prenatal providers
- Audit of provider medical records

State-specific Strategies. New Jersey and New York are “seasoned” sites; Florida demonstrates a more recent but successful surveillance/intervention.

New Jersey —Diane Abatemarco

- Resources/information are available to other sites especially PRODAS, SAS analysis programs, especially for merging registries.
- NJ program is a hybrid of surveillance and prevention with strong outcome evaluation component.
- Perinatal prevention is done by mobile outreach through local committees with a surveillance representative on these outreach committees.
- Tools
    - HIV/AIDS Reporting System (HARS)
    - Survey of Childbearing Women (SCBW) - Local funds to continue ZIP-code– based risk
    - Surveillance to Evaluate Perinatal Prevention (STEP) - Medical abstract survey to evaluate maternal-infant pairs 1994 to present. Looks for missed opportunities (otherwise known a enhanced perinatal HIV surveillance).
    - Birth certificate matching
    - Studies - SHAS or graduate student studies
    - New HIV counseling information module on birth certificate
    - Exploring laboratory database as potential use of provider change in testing patterns

Review of NJ Studies

- Knowledge, attitudes, beliefs, and intentions surrounding ZDV use—pregnant women, more knowledge relates to more adherence
- Diffusion of HIV counseling by NJ obstetricians/gynecologists
- Factors related to pregnant women ZDV use—algorithm of how to look at risk factors for ZDV use

Lessons Learned from STEP in NJ. Large number of women receive poor or no prenatal care. Next "step" for enhanced perinatal surveillance in NJ

- Combination therapy, adverse events, resistance
- Viral load (April 2000 law change to include reporting of viral load)
- Mode of delivery (elective cesarian section for HIV prevention)

New York State — Jim Tesoriero, Brian Gallagher

NY Task Force for the Prevention of Perinatal HIV Transmission Evaluation Workgroup Goals

- Increase prenatal care use to $95%.
- Increase rate of prenatal HIV testing to 90% in hospitals targeted for testing.
- Increase percentage of HIV-infected women and infants who receive full 076 antiretroviral therapy from 51% to 90%.
- Reduce perinatal HIV transmission in each target area from 12% to <5%.

Community Action for Prenatal Care (CAPC) Initiative

- Target areas are Bronx, Brooklyn, Manhattan, Buffalo. Focus on areas by ZIP-code–based risk.
- Uses local community planning committees
- Mobilizes existing resources (HIV, substance abuse, MCH) rather than create new.
- Trains prenatal care providers and outreach staff members.
- Hopes to eventually expand training beyond target areas.
- Plans to offer technical assistance to hospitals with high seroprevalence and low testing rates.

NY Task Force Evaluation Workgroup

Represents a wide range of agencies
Monitors program implementation.
Reviews process and outcome data.
Recommends program improvements.
Directs implementation team.
Develops evaluation strategies.

Further Questions/Issues

What are the important research questions?
How can information be abstracted from existing data?
How can we show that gains result from our interventions, not from other programs?
When are individual, rather than aggregate, data necessary?
How much data collection responsibility should be placed on community workers?

Process Measures

Outreach (number efforts, number contacts, location of contact)
Intake data (number, source, demographics and risk, pregnancy status, prenatal care status, HIV status, services received)
Referrals data (number, type, compliance)
Training (outreach workers and hospitals)

Outcome Measures

- Prenatal care use
- HIV testing patterns and rates
- Receipt of full 076 antiretroviral regimen
- Treatment rates
- Birth outcomes (e.g., birthweights)
- Knowledge, attitude, and behavior changes resulting from training (outreach workers and hospitals)

	HIV Antibody Status	Prenatal Care Counseling and Testing	Antiretroviral Use	HIV Infection Status
HIV Test History		X		
Newborn Screen	X			X
Charts (prenatal, labor, delivery, infant)		X	X	X
PCR Results				X

Resources Available to Other States

- Variables added to charts re: HIV
- Provider form
- Newborn screening form

Florida — Marlene LaLota

Evaluation of Perinatal HIV Prevention Programs

- The program began in 1994 after Pediatric AIDS Clinical Trials Group (PACTG) 076.
- It is multipronged (consumer and provider) with a wide variety of agencies.
- It is overseen and directed by an interdisciplinary workgroup.
- It is supplemented by a 1996 Florida law, which required mandatory counseling and voluntary testing.

Twofold Strategy: Educate 1) providers and 2) consumers

1. Provider Resources
   - Packet
   - Video
   - Medicaid contract
   - QI Review
   - Seminars
   - Newsletters
   - Ongoing provider training and education

2. Consumer Approach
   - Social marketing
   - *Woman's Time* newsletter

Targeted Outreach to Pregnant Women Act (provides outreach to pregnant women without prenatal care)

Evaluation Resources

- Perinatal provider survey
- PRAMS
- Pediatric HIV/AIDS surveillance data
- AIDS education training center contract
- University of Florida contract
- Hospital record and policy review (11 counties)

Evaluation Plan

- Develop assessment models to evaluate social marketing (Miami-Dade County).
- Characterize secondary data sources.
- Develop data link.

Because this is a new program, they are working to analyze and integrate data to develop an epi profile.

New/Proposed Strategies

- Electronic birth certificate for testing data
- Add variables to counseling and testing (still using old seroprevalence data)
- SCBW from 1995 (CDC)
- Children's AIDS network database (9 pediatric centers, >95% HIV-infected children, and information on maternal-infant pairs)

Workshop F: Summary

Further strategies to be developed

- Share information.
- Develop timelines.
- Distribute summaries.

Group Discussion/Questions

- How does the perinatal prevention program fit into the overall state evaluation plan?
- How can we assess the impact of perinatal programs in low infection/seroprevalence states?
- How can we integrate prevention, surveillance, and other new partners?